

National Institute of Arthritis and Musculoskeletal and Skin Diseases Information Clearinghouse

Annual Report

July 1, 2000–June 30, 2001

This annual report for the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) Information Clearinghouse highlights 2000–2001 contract year activities in the following task areas: management and planning; inquiry and mailing services; materials development; database development, maintenance, and searches; support for interactive information systems; communication research and evaluation; outreach and promotion; conference support; and graphic design, production, and reproduction services. Tables and charts show progress and trends for various areas. Each task includes a synopsis of clearinghouse activities and a list of future steps.

SUMMARY OF MAJOR ACCOMPLISHMENTS

The 2000–2001 reporting period was a productive and exciting one for the clearinghouse—staff responded to more than 28,500 inquiries and disseminated over 713,000 publications, both significant increases over previous years of operation. As well, Year three of operation of the clearinghouse by Eagle Design & Management, Inc., saw a marked rise in both the total number and percentage of inquiries coming from announcements in the media. This year, almost 45% of requestors heard about the NIAMS Information Clearinghouse from the media.

While clearinghouse staff continued to exhibit at or support NIAMS staff at 17 professional conferences this year, participation was added at 39 health fairs and smaller conferences, a major increase. Through these, many new intermediaries, health professionals, and service organizations were made aware of the clearinghouse and its services.

More than 295,000 publications were sent in bulk to the Consumer Information Center (CIC) in Pueblo, CO, a practice started the previous year. These bulk shipments, totaling nearly three times the amount shipped last year, comprised new titles, as well as additional amounts of materials already depleted by Pueblo mailings. Other bulk mailings to individual requestors, acting as intermediaries, continued at a high rate.

Production of new and revised publications continued at a peak rate during this contract year. Three new publications were designed, produced, and printed. Four revisions of previously issued publications were produced. Nine Questions & Answers publications were revised and reissued in a new booklet format. Nine publications were also produced in a large-print format for ease of reading. Twenty-three items were updated or newly

produced and coded for the NIAMS Web site. And last, continuing the effort toward bilingual access, four publications were issued in Spanish-language format.

During the past year, a new staff member was added to fill the opening in inquiry response. [redacted] joined the staff as an information specialist and, in the ensuing period, has assumed the myriad duties involved in tracking publications on the NIAMS' behalf. In addition, the year ended with a new project manager for the clearinghouse, [redacted]. Current staff continues to attend bimonthly meetings with the Project Officer and senior staff of the Office of Communication and Public Liaison (OCPL). These meetings, coupled with daily e-mail and telephone calls, maintain open communication channels between the NIAMS and the project manager and staff.

National Institute of Arthritis and Musculoskeletal and Skin Diseases
Information Clearinghouse

List of Major Accomplishments: Year 3

- ◆ In Year 3, NIAMS Information Clearinghouse staff responded to the information needs of patients, families, researchers, health care professionals, and NIAMS staff by answering 28,560 inquiries (a 39 percent increase over Year 2) and distributing 713,340 publications (a 51 percent increase over Year 2). Of the requests, 413 were provided with custom searches and 1,248 included attachments, with the material provided from inventory.
- ◆ The 10 most requested publications (and the number distributed) were as follows:
 - *Do I Have Arthritis?* (131,451)
 - *Questions & Answers About Arthritis Pain* (62,133)
 - *Questions & Answers About Arthritis and Exercise* (61,243)
 - *Questions & Answers About Hip Replacement* (55,696)
 - *Handout on Health: Osteoarthritis* (43,177)
 - *Handout on Health: Systemic Lupus Erythematosus* (31,673)
 - *How to Find Medical Information* (26,565)
 - *Handout on Health: Atopic Dermatitis* (18,197)
 - *Questions & Answers About Fibromyalgia* (16,562)
 - *Questions & Answers About Sjögren's Syndrome* (12,326)
- ◆ Clearinghouse staff responded quickly and with aplomb to an upsurge in requests following the announcement of several of our publications in over 100 newspapers and newsletters nationwide in Contract Year 3. The following titles were listed and specifically requested. All orders were filled by clearinghouse staff:
 - *Alopecia Areata Information Packet*
 - *Do I Have Arthritis? (¿Tengo Artritis?)*
 - *Fibromyalgia Information Packet*
 - *How to Find Medical Information*
 - *Questions & Answers About Knee Problems*
 - *Questions & Answers About Sjögren's Syndrome*
 - *What Black Women Should Know About Lupus*
- ◆ More than 295,000 publications were sent in bulk to the CIC, a Federal information clearinghouse sponsored by the U.S. General Services Administration.
(See Appendix 12: *NIAMS Information Clearinghouse Publications Sent to the Consumer Information Center in Pueblo, CO.*)

- ◆ In the past year, almost 45 percent of inquirers heard about the clearinghouse or its publications from media listings (i.e., journals, newspapers, magazines, newsletters, radio, or television). In the year before, slightly more than 27 percent of inquiries were the result of media listings.
- ◆ The booklet, *The Many Shades of Lupus*, a replacement for *What Black Women Should Know About Lupus*, was completed and sent to the printer.
- ◆ Text revisions were completed for *Lupus: A Patient Care Guide for Nurses and Other Health Professionals*, and the booklet was printed and placed in inventory.
- ◆ *Questions & Answers About Sjögren's Syndrome* and *Handout on Health: Scleroderma* were completed, printed, and placed in stock.
- ◆ *Progress and Promise*, the NIAMS 15th anniversary booklet, was completed for the NIAMS Coalition meetings and was well received.
- ◆ In Year 3, a total of 496 new records were cataloged and abstracted for the AR subfile of the Combined Health Information Database (CHID), which is posted on the *CHID Online* Web site. New records were added in October 2000 (n=150), January (n=121), and April (n=100). Also, 125 new records will be added in July 2001. Further, 99 outdated and out-of-print records were deleted. The AR subfile remained the third most frequently searched subfile in CHID.
- ◆ In preparation for a brainstorming session on publication development with NIAMS staff, clearinghouse staff did extensive background searches to determine topics for new publications, evaluating several resources to develop a list of the most commonly requested topics.
- ◆ Continuing education for clearinghouse staff has included cross-cultural competence and cultural sensitivity, with a focus on the Hispanic community, and communicating in plain language.
- ◆ Requests continued in several formats. More than 28 percent of our callers used our toll-free phone line. Implementing a new script in plain language made our toll-free line more user-friendly. An automated bounce-back response was added to e-mail to provide immediate confirmation to people requesting information from the clearinghouse. A total of 1,284 bulk orders were filled, distributing 110,240 publications.
- ◆ Clearinghouse staff completed reformatting 9 out of 26 Questions & Answers fact sheets as booklets. Additionally, a style guide for these booklets was written and distributed to both NIAMS and clearinghouse staff for use as new and revised publications are processed by writers and editors in both locations.
- ◆ Clearinghouse staff provided full exhibit support for the 11 NIAMS-staffed conferences, including booth arrangements, furnishings, materials selection, and logistics. Setup and dismantling services were provided for several.
- ◆ Clearinghouse staff provided the same full exhibit support to 6 conferences staffed by the clearinghouse. We provided travel arrangements, setup, and dismantling for all 6 of these exhibits, as well.

- ◆ Clearinghouse staff provided materials and logistics for all 39 health fairs scheduled by the NIAMS and provided setup/dismantling services for many of them.
- ◆ In terms of conference support, clearinghouse staff developed materials for and assisted the OCPL director with a poster session at the American College of Rheumatology meeting in Philadelphia, prepared and assembled 40 packets of information for the NIAMS Coalition Planning meeting on January 17th, and assembled a total of 149 folders for the NIAMS Coalition advance mailing and coalition meetings. In addition, 50 folders were sent to the American Academy of Orthopaedic Surgeons; clearinghouse staff arranged delivery of two special orders to two coalition organizations; and clearinghouse staff assembled 60 folders for the Lupus Foundation of America contingent visiting the National Institutes of Health (NIH) during Coalition Week.
- ◆ Clearinghouse staff conducted research on NIH and Federal national health initiatives and incorporated the information into the National Health Partnership Program proposal submitted to the Institute for review. In addition, clearinghouse staff helped OCPL staff publicize the anticipated opening of the NIAMS Community Health Center, the keystone of the partnership initiative.
- ◆ Eagle Design's graphics staff designed the following:
 - Spanish fact sheets for
 - Community Health Center
 - Health Partnership Program
 - Sjögren's Syndrome
 - Osteoarthritis
 - Pediatric Rheumatology Clinic fact sheet
 - Community Health Center brochure
 - Health Partnership Program stationery
 - *The Many Shades of Lupus* illustrations
 - Signage for the NIAMS Health Partnership Program and Intramural Research Program meetings
- ◆ Clearinghouse staff conducted a complete review of NIAMS warehouse space and inventory process and storage. A sample of all inactive inventory materials was retrieved for evaluation of continued inventory status.
- ◆ A comprehensive list of all printed materials was developed by clearinghouse staff for tracking reprinting timelines and monthly distribution needs.
- ◆ Clearinghouse staff prepared the annual (fiscal year and contract/operations year) inquiry response statistics data tables and graphs for the NIAMS Coalition meeting and other NIAMS reporting needs.
- ◆ The *NIAMS Information Clearinghouse Procedures Manual* was revised and submitted to the Institute. It serves current staff as a formal set of guidelines and an

everyday reference. As new staff join the project, it will serve as a training guide and provide insight into the specific clearinghouse functions and requirements.

- ◆ New screens and features were added to Inquiry Tracking and Inventory Management System (ITIMS) to collect more detailed information about media requests handled by NIAMS staff. Reports were developed to show the number of press or media calls, the source of those calls, any referrals made, the subject(s) requested, and the details of each call.
- ◆ Clearinghouse staff prepared and distributed 13 NIAMS special mailings and press releases, sending mailings to 18,772 people whose addresses were accessed through the ITIMS.

TASK 1: MANAGEMENT AND PLANNING

The management staff of the NIAMS Information Clearinghouse continues to be dedicated to effective administration, ensuring efficient dissemination of materials, innovative promotion strategies, and effective and timely materials development processes. Contributing to this highly successful project is the continued team approach to clearinghouse operations, which includes regular staff meetings at which overall clearinghouse operations are evaluated and improved on.

Year 3 Activities:

- ◆ Monthly progress reports were submitted to the Contracting Officer and Project Officer on or before the 20th of every month.
- ◆ Clearinghouse staff submitted the monthly NIAMS inquiry tracking report to the NIAMS OCPL director on or before the 20th of every month.
- ◆ ITIMS was customized to provide statistical information in the graphical format requested by the Project Officer.
- ◆ The project manager completed the Year 3 Annual Performance and Operating Plan.
- ◆ Clearinghouse staff revised the *NIAMS Information Clearinghouse Procedures Manual*.
- ◆ Staff participated in an information-sharing brainstorming session at the NIAMS to discuss publication development plans for the next two years.
- ◆ Internal staff meetings and publication tracking meetings were held regularly throughout the month.
- ◆ Clearinghouse staff presented and attended in-house continuing education sessions designed to improve skills and enhance our knowledge of clearinghouse operations, health issues, and communication skills.

TASK 2: INQUIRY AND MAILING SERVICES

Year 3 continued the marked upward trend for all inquiry and mailing services for the NIAMS Information Clearinghouse. Inquiries increased more than 39 percent, compared with Year 2, from 20,514 to 28,560 and the number of publications ordered through all sources increased 51 percent from 472,977 to 713,719. (Please refer to *APPENDIX 1: Monthly Comparison of Requests Received* and *APPENDIX 2: Monthly Comparison of Publications Ordered*.) Direct promotion of publications to health professionals, increased exposure of the clearinghouse through the media, and increased Internet competency by consumers spurred this exponential growth. The use of the NIAMS Information Clearinghouse toll-free line increased to 28.2 percent of all inquiries, and implementing a new script in plain language made our toll-free line more user-friendly.

Year 3 Activities:

◆ **Inquiry Response:**

- *Staff Training:*
 - A complete training program for new staff, which includes an understanding of the mission, scope, and services of the NIAMS and the role and services of the clearinghouse, was continued. Training instructions also include explaining the roles and responsibilities of the NIAMS/NIAMS Information Clearinghouse staff, response materials and services, standard and custom response procedures, NIAMS Coalition and referral organizations, appropriate Internet resources, and daily exposure to online news health bulletins.
- *Response to Public Inquiries:*
 - In Year 3, NIAMS Information Clearinghouse staff responded to a total of 28,560 inquiries. Most inquiries, almost 34 percent (9,574 requests), were received through the U.S. mail. A total of 28.2 percent (8,049 requests) were received via the toll-free number, while 13.6 percent (3,873 requests) came through the NIAMS Information Clearinghouse phone line. E-mail requests composed 18.7 percent of total inquiries (5,327). The response to most requests, almost 87 percent, was to mail an information package or other publication. (Please refer to *APPENDIX 3: Analysis of Requests Received and Responses Given.*)
 - Both screening and response times in answering inquiries were mostly within the 1- to 2-minute range. (Please refer to *APPENDIX 4: Requests by Response Time* and *APPENDIX 5: Requests by Screening Time.*)
 - The vast majority of requesters (74.7 percent) were patients. Exactly 14.2 percent of the requests for this year were from health care professionals. (Please refer to *APPENDIX 6: Requester Profile.*)
 - Requesters heard about the NIAMS Information Clearinghouse from a variety of sources, including information sources such as directory listings (5.6 percent); media listings (44.9 percent); Federal agencies (3.3 percent); clearinghouse publications (9.7 percent); the Internet (17.6 percent); health care professionals (1.9 percent); and other information sources such as family members, other patients, or friends (1.1 percent). About 1.1 percent of users were repeat callers. (Please refer to *APPENDIX 7: Referral Source Profile.*)
 - Most requests were about arthritis and rheumatic diseases; general arthritis questions comprised 18.6 percent of the requests, lupus inquiries comprised 8.2 percent, fibromyalgia inquiries comprised 5.9 percent, rheumatoid arthritis inquiries comprised 3.1 percent, and osteoarthritis inquiries comprised 4.4 percent of all requests. More than 8.6 percent of the requests concerned skin diseases. Requests for information about musculoskeletal diseases also comprised almost 16.2 percent of all inquiries. (Please refer to *APPENDIX 8: Analysis of Requests by Disease Area.*)

- As in Year 1 and 2, most requests came from people in New York (2,422), followed by Florida (2,144) and California (2,072). (Please refer to *APPENDIX 9: Summary of Requests Received by State, U.S. Territory, Canadian Province, or Other Country.*)
- *Standard Response Materials*
 - Nine of the 26 Questions & Answers fact sheets were reformatted as booklets by clearinghouse staff.
 - Additional form letters were developed by NIAMS Information Clearinghouse staff in an effort to streamline inquiry response.
- ◆ **Publication Storage, Receipt, and Distribution:**

A total of 713,340 publications were distributed in Year 3.
- ◆ **Data Collection, Tracking, and Reporting System:**
 - Overall, the five most distributed publications were
 - *Do I Have Arthritis?* (131,451)
 - *Questions & Answers About Arthritis Pain* (62,133)
 - *Questions & Answers About Arthritis and Exercise* (61,243)
 - *Questions & Answers About Hip Replacement* (55,696)
 - *Handout on Health: Osteoarthritis* (43,177)

(Please refer to *APPENDIX 10: Active Inventory* and *APPENDIX 11: NIAMS Inactive Inventory.*)

- E-mail requests increased from 4,042 in Year 2 to 5,325 in Year 3, almost a 32 percent increase. We anticipate continued growth in this area as more people visit the NIAMS Web site. E-mail is also an increasingly popular medium for disseminating health materials to patients, consumers, and medical professionals.

Next Steps:

- ◆ Continue to analyze and refine current standard and custom response materials in the NIAMS Information Clearinghouse library and update resources and responses.
- ◆ Refine quality control efforts—ensuring that inquiries are appropriately responded to and that all phases of request processing are accurate.
- ◆ Foster continued NIAMS/clearinghouse communication on any new developments information/procedures for inquiry response.

TASK 3: MATERIALS DEVELOPMENT

Year 3 Activities:

The NIAMS Information Clearinghouse staff was extremely busy with materials development in Year 3. Staff supported the development of all new publications, including two in the Question & Answers fact sheet series, one Handout on Health booklet, and one in the Materials for Special Audiences series. Staff also completed revisions on the Questions & Answers fact sheets and converted them into the new booklet format. The following is a list of publications and products that NIAMS Information Clearinghouse staff developed:

♦ **Publications:**

- NIAMS Information Clearinghouse staff completed regular, large-print, and online versions of the following Questions & Answers fact sheets:
 - *Questions & Answers About Heritable Disorders of Connective Tissue*
 - *Questions & Answers About Sjögren's Syndrome*
- NIAMS Information Clearinghouse staff completed a regular and large-print version of the *Handout on Health: Scleroderma* booklet.
- NIAMS Information Clearinghouse staff completed the new limited-literacy booklet, *The Many Shades of Lupus*.
- NIAMS Information Clearinghouse staff completed *Progress and Promise*, the 15th anniversary booklet for the NIAMS.
- NIAMS Information Clearinghouse staff completed two issues (fall 2000 and spring 2001) of *IRPartners*, the NIAMS quarterly newsletter.
- NIAMS Information Clearinghouse staff completed a brochure for the new NIAMS Center.
- NIAMS Information Clearinghouse staff completed Spanish fact sheets for the Community Health Center, the Health Partnership Program, Sjögren's Syndrome, and Osteoarthritis.
- NIAMS Information Clearinghouse staff completed revisions of the regular, large-print, and online versions of the following Questions & Answers fact sheets and converted them into booklet format:
 - *Questions & Answers About Arthritis and Exercise*
 - *Questions & Answers About Arthritis Pain*
 - *Questions & Answers About Avascular Necrosis*
 - *Questions & Answers About Hip Replacement*
 - *Questions & Answers About Knee Problems*
 - *Questions & Answers About Polymyalgia Rheumatica and Giant Cell Arteritis*
 - *Questions & Answers About Raynaud's Phenomenon*

- *Questions & Answers About Shoulder Problems*
- *Questions & Answers About Vitiligo*
- NIAMS Information Clearinghouse staff completed revisions to the following publications:
 - *Do I Have Arthritis? (¿Tengo Artritis?)*
 - *Lupus: A Patient Care Guide for Nurses and Other Health Professionals*
 - *How to Find Medical Information*
 - *Childhood Sports Injuries and Their Prevention: A Guide for Parents With Ideas for Kids*
- NIAMS Information Clearinghouse staff submitted manuscripts of the following publications for review:
 - *Questions & Answers About Autoimmune Diseases* fact sheet
 - *Handout on Health: Sports Injury* booklet
- NIAMS Information Clearinghouse staff developed a style guide for use by all writers and editors involved in the creation/revision of the Questions & Answers booklets.
- NIAMS Information Clearinghouse staff continued to make copies of the Questions & Answers fact sheets and the Information Packages.
- ♦ **Projects:**
 - NIAMS Information Clearinghouse staff also completed the following projects:
 - NIAMS Health Partnership Program stationery
 - NIAMS Information Clearinghouse Publication Order Form
 - NIAMS Information Clearinghouse letterhead
 - NIAMS promotional flyer for the Sjögren's Syndrome booklet
 - NIAMS posters for the Health Partnership Program and Intramural Research Program meetings
 - NIAMS easy-to-read bookmark
 - NIAMS Spanish bookmark
 - NIAMS pens
 - NIAMS transparencies
 - NIAMS pocket folders
 - NIH banner and other signs for NIAMS exhibits and health fairs
 - NIH Pediatric Rheumatology Clinic erasers
 - NIH Pediatric Rheumatology Clinic pencils

Next Steps:

- ♦ Continue helping with other projects as needed.
- ♦ Continue to provide support in the materials development process.
- ♦ Continue to make copies of the Questions & Answers fact sheets and the Information Packages.

- ◆ Continue to format publications as requested by the NIAMS.
- ◆ Continue refining promotion plans for the various publications.

TASK 4: DATABASE DEVELOPMENT, MAINTENANCE, AND SEARCHES

Year 3 Activities:

We continued to build up our reference collections and resources to help our information specialists provide callers with the most up-to-date and complete answers we can. The AR subfile of CHID continued to grow with the addition of almost 500 new records. Also, clearinghouse staff continued to expand clearinghouse reference materials by acquiring more journals, newsletters, articles, books, and patient education materials. In addition, new organizations were added and older entries were updated in the in-house resource organization directory used by our information specialists.

We continued to update mailing list records and provide NIAMS with mailing labels as requested.

The issue of a NIAMS Coalition Organizations database specifically for NIAMS use was addressed.

Following is a list of the accomplishments in database development, maintenance, and searches:

◆ **Maintaining the AR subfile of CHID:**

- A total of 496 new items were cataloged and abstracted for the AR subfile of CHID. Also, 99 outdated items were deleted from the subfile. (Please refer to *APPENDIX 13: Format of Items Added to the CHID AR Subfile.*)

Type of Material	Number of Items Added to CHID*
Journal Articles	280
Brochures	126
Fact Sheets	62
Book Chapters	27
Miscellaneous Print Formats	1
TOTAL	496

* Totals include records processed and added in October 2000 and January, April, and July 2001.

- *CHID Online* usage totaled 49,295 searches of the AR subfile; a total of 2,347,413 CHID searches were done. The number of online searches of the AR subfile, on average the third most frequently searched subfile, was down 4.8 percent from the previous year; overall CHID searches were down 4.7 percent from the previous year. Search activity in the AR subfile in *CHID Online* was as follows. (Please refer to *APPENDIX 14: Monthly Comparison of Searches on the AR Subfile of CHID.*)

Month	Number of Searches of the AR Subfile	Total Number of Searches of CHID and Its Subfiles*	Percentage of Total Number of Searches
Jul 2000	4,144	177,339	2.34
Aug 2000	3,828	182,107	2.10
Sep 2000	3,276	181,376	1.81
Oct 2000	3,825	215,256	1.78
Nov 2000	4,107	199,813	2.06
Dec 2000	3,381	154,473	2.19
Jan 2001	4,983	221,788	2.25
Feb 2001	4,245	207,742	2.04
Mar 2001	5,072	221,666	2.29
Apr 2001	4,418	214,147	2.06
May 2001	4,100	191,611	2.14
Jun 2001	3,916	180,095	2.17
Yearly Total:	49,295	2,347,413	2.10

* This equals the total number of searches of CHID as a whole plus each of its subfiles.

◆ Identifying, Acquiring, and Screening:

- Several patient education publications from NIAMS Coalition organizations (including the Lupus Foundation of America), other health-related organizations (including the American Podiatric Medical Association, the National Association for Pseudoxanthoma Elasticum, the American College of Foot and Ankle Surgery, and the American Academy of Family Physicians), and commercial producers (including Krames/StayWell, HOPE Publications) were obtained for inclusion in the AR subfile.
- Journal articles identified by clearinghouse staff were screened and copied for inclusion in future loads. Staff continued to read appropriate journals as part of the continuing education program and review them as candidate items for the AR subfile.
- Staff members continued identifying items for future loads by screening catalogs and other sources.
- Medical references and textbooks were requested from publishers to help staff with inquiry response and to develop new publications.

♦ **Establishing, Updating, and Maintaining Mailing Lists:**

- Clearinghouse staff continued to update the NIAMS Coalition mailing lists as edits were requested.
- Mailing labels, in the following amounts, were requested by the NIAMS and were printed and delivered within the contract period:

Month and Year	Total Number of Labels Printed
Jul 2000	242
Aug 2000	977
Sep 2000	2,075
Oct 2000	3,493
Nov 2000	2,131
Dec 2000	2,360
Jan 2001	1,874
Feb 2001	840
Mar 2001	837
Apr 2001	1,424
May 2001	345
Jun 2001	2,174
Total Printed:	18,772

♦ **Establishing a NIAMS/NIAMS Information Clearinghouse Resource Referral Database:**

- After evaluating the existing database and having discussions, the NIAMS decided to ask Eagle Design to develop a new database of NIAMS Coalition Organizations, for NIAMS use exclusively, under a separate contract.

Next Steps:

- ♦ Continue adding materials to the AR subfile. Continue deleting outdated records and modifying others as needed.
- ♦ Continue the acquisitions process for CHID by screening journal and newsletter articles and contacting professional and voluntary organizations (especially members of the Coalition of Professional and Voluntary Organizations Concerned With the Programs of the NIAMS) and requesting new publications (ongoing).
- ♦ Update the mailing list as needed.
- ♦ Continue to provide mailing labels to NIAMS staff as requested.
- ♦ Make changes to the Resource and Referral Database as requested.

TASK 5: SUPPORT FOR INTERACTIVE INFORMATION SYSTEMS

Year 3 Activities:

The electronic publishing staff continued to support NIAMS/NIAMS Information Clearinghouse efforts. Staff members quickly formatted all new publications for placement on the Web. Following is a list of projects the electronic publishing staff has supported:

♦ **Web Site Design, Development, and Maintenance:**

- During the past year, the electronic publishing staff incorporated edits to existing pages and created many new documents on the NIAMS Web site. The following titles were completed and ftp'd:
 - Cartilage Biology and Autoimmunity Branches
 - *Data and Safety-Monitoring Guidelines*
 - *Do I Have Arthritis?* bilingual booklet
 - Fast Facts Service reference removal
 - *How to Find Medical Information* booklet
 - *IRPartners Summer 2000* newsletter
 - *IRPartners Fall 2000* newsletter
 - Lupus Guide Order Form
 - Monthly Web maintenance tests
 - NIAMS Calendar of Events
 - *Osteoporosis: Progress and Promise*
 - Plotz story
 - *Preventing Childhood Sports Injuries* fact sheet
 - *Progress and Promise*—NIAMS 15th Anniversary booklet
 - Publication Order Form and Online Order Form
 - *Questions & Answers About Avascular Necrosis* booklet
 - *Questions & Answers About Heritable Disorders of Connective Tissue* fact sheet
 - *Questions & Answers About Juvenile Rheumatoid Arthritis* fact sheet
 - *Questions & Answers About Polymyalgia Rheumatica and Giant Cell Arthritis* booklet
 - *Questions & Answers About Sjögren's Syndrome* booklet
 - *September 2000 Shorttakes*
 - Specialist Involvement Improves Care for People With RA
 - Spotlight on Research: Common Origins Found for Hair, Skin Cells
- The following titles are in the process of being formatted:
 - *Handout on Health: Scleroderma* booklet
 - *Questions & Answers About Arthritis Pain* booklet
 - *Questions & Answers About Hip Replacement* booklet

◆ **Faxback System Support:**

In Year 3, clearinghouse staff continued to maintain, evaluate, and eventually terminate the NIAMS Information Clearinghouse Fast Facts (faxback system).

- Maintenance activities included adding the following new publications to the system:
 - *Preventing Childhood Sports Injuries* fact sheet
 - NIAMS Funds Multiple Research Grants in Osteogenesis Imperfecta press release
- A total of 1,106 calls were received. Most of them were from people who hung up after realizing that they needed to call from their fax machine rather than a regular phone. A few were occurrences where callers proceeded to download documents and test calls.
- After reevaluating the faxback system and comparing it with other inquiry methods, the NIAMS decided to discontinue it. Clearinghouse staff developed and recorded a voice script and produced a fact sheet with clearinghouse contact information to be used after the system was discontinued.
- The NIAMS Fast Facts was terminated in April, and a recorded voice message provides callers with alternate numbers and Internet addresses to meet their information needs.

Next Steps:

- ◆ Convert documents to HTML for placement on the Web site, as requested.

TASK 6: COMMUNICATION RESEARCH AND EVALUATION

Year 3 Activities:

- ◆ The clearinghouse librarian met with the Project Officer to discuss the status of the evaluation of the MEDLINE^{plus} project. A schedule was established to review over 54 topics covered by the Institute. Clearinghouse staff submitted the MEDLINE^{plus} evaluation project to the Project Officer for review.
- ◆ Clearinghouse staff continued gathering information to aid in the development of the following publications:
 - *Questions & Answers About Heritable Disorders of Connective Tissue*
 - *Questions & Answers About Autoimmune Disease*
 - *Handout on Health: Sports Injury*

- ◆ Clearinghouse staff met with NIAMS staff to discuss the NIAMS Health Partnership Program: A NIAMS Diversity Outreach Initiative. Clearinghouse staff conducted research on NIH and Federal national health initiatives and incorporated information into the National Health Partnership Program proposal, which was submitted in revised form to the Institute for review in November. We await feedback from the Institute after the NIAMS Community Health Center opens in the Cardozo area of Washington, DC, in July 2001.
- ◆ Clearinghouse staff attended the 2nd meeting of the Health Partnership Program African American Community Partners at the NIAMS on October 11, 2000.

Next Steps:

- ◆ Continue researching textbooks and medical journals to gather information for the development of the new patient education materials.
- ◆ Continue work on the NIAMS Health Partnership Program as requested.

TASK 7: OUTREACH AND PROMOTION

Year 3 Activities:

◆ **Networking and Liaison:**

- Information about the NIAMS Information Clearinghouse and its publications were included in over 100 newspapers and magazines in Contract Year 3. The NIAMS publications *How to Find Medical Information*, *Do I Have Arthritis?*, *Questions & Answers About Knee Problems*, and *Questions & Answers About Sjögren's Syndrome* received the most press and resulted in the most requests to the clearinghouse. Media attention varied from the *New York Times* Sunday Magazine section to the *Missoulian* of Missoula, Montana, and included most States in between. *New Choices* magazine (April 2001), from the publisher of *Reader's Digest*, and the *Washington Post* Health Section (January 2, 2001) were among this year's NIAMS media promoters.

◆ **Exhibit Support:**

- The NIAMS Information Clearinghouse supported 56 professional meetings and health fairs in Year 3. This support included some or all of the following services: booth arrangements, furnishings, materials, and exhibit logistics. A total of 33,344 publications were distributed through exhibits this year, twice as many as in Year 1 (15,302) and a continued increase over Year 2 (30,662). To evaluate the effectiveness of each conference, an exhibit report was completed by clearinghouse staff after each professional meeting. (See the attached *NIAMS/NIAMS Information Clearinghouse Exhibit Reports*.)

- NIAMS-staffed conferences supported by the NIAMS Information Clearinghouse in Year 3 were as follows:
 - American Indian Science and Engineering Society (AISES)
 - Bowie State University Senior Job Fair
 - Congressional Black Caucus Foundation (CBCF)
 - Minority Health Professions Foundation (MHPF)
 - Montgomery County Women's Fair
 - National Council of La Raza
 - National Medical Association (NMA)
 - National Minority Research Symposium (NMRS)
 - Research Centers in Minority Institutions (RCMI)
 - Society for the Advancement of Chicanos and Native Americans in Science (SACNAS)
 - University of Maryland Multi-Ethnic Student Career and Job Fair
- Conferences supported and staffed by the NIAMS Information Clearinghouse in Year 3 were as follows:
 - American Academy of Family Physicians (AAFP)
 - National Conference of Nurse Practitioners (NCNP)
 - American College of Rheumatology (ACR)
 - Dermatology Nurses Association (DNA)
 - American Academy of Dermatology (AAD)
 - American Academy of Physician Assistants (AAPA)
- In addition, the NIAMS Information Clearinghouse supported the following health fairs in Year 3 with material and logistic services.
 - Community Forum in Washington, DC
 - National Association of Geriatric Nurses
 - NIH Hispanic Heritage Celebration
 - La Clinica del Pueblo, Children and Adolescents
 - La Clinica del Pueblo
 - East of the River Health Care Symposium
 - Fiesta Musical 2000
 - Mini-Med School
 - Campbell AME Church Health Fair
 - National Capitol YMCA
 - NIH Community Office of Community Liaison Health Fair
 - Luther Rice Memorial Baptist Church
 - Senior Citizens Counseling and Delivery Service
 - Baptist Convention Annual Meeting
 - St. Mary's Court
 - Columbia Senior Center
 - D.C. Armory
 - NIH Martin Luther King Day
 - Bell Multicultural High School Fair

- CVC Job Fair
- Educational Organization for United Latin Americans
- Central Missouri State University Wellness Fair
- National Hispanic Medical Association
- American Academy of Orthopaedic Surgeons
- Columbia Road Health Services
- Beta Kappa Chi
- Eliminating Health Disparities by 2010
- Suburban Hospital Health Fair
- NIH Take Your Kids to Work
- University of Virginia, Eliminating Racial and Ethnic Health Disparities
- Langley Park Day Health Fair
- Administration on Aging Health Fair
- NIEHS Minority Student Health Fair
- NIH National Women's Health Week
- Annual Senior Citizens' Day
- Women's Health Summit, Rep. R. Frelinghuysen
- American College of Nurse Midwives
- National Association of Hispanic Journalists
- Scleroderma Foundation National Conference

Next Steps:

- ◆ Continue to analyze and streamline the exhibit process and communicate with everyone involved for maximum promotional effectiveness.
- ◆ Continue ongoing arrangements for Year 4 exhibits.

TASK 8: CONFERENCE SUPPORT

Year 3 Activities:

The NIAMS Information Clearinghouse staff provided support for all requested NIAMS-sponsored events. Staff helped prepare and distribute meeting information, create meeting materials, and prepare conference summaries. Activities included the following:

- ◆ Clearinghouse staff prepared the NIAMS Ad-Hoc Advisory Council Meeting minutes.
- ◆ Clearinghouse staff prepared the NIAMS Community Health Center Forum minutes.
- ◆ Clearinghouse staff helped the NIAMS OCPL staff prepare handouts and slides for the NIAMS council meeting.
- ◆ Clearinghouse staff prepared handouts for the Health Partnership Program African American Community Partners meeting.
- ◆ Clearinghouse staff developed materials for and assisted the OCPL director with a poster session at the American College of Rheumatology meeting in Philadelphia.

- ◆ Clearinghouse staff assisted NIAMS by preparing handouts and materials and providing support for a NIAMS-sponsored reception at the American College of Rheumatology meeting in Philadelphia.
- ◆ Clearinghouse staff set up and dismantled the NIAMS floor exhibit for the Health Disparities in Arthritis and Musculoskeletal and Skin Diseases Conference at NIH.
- ◆ Clearinghouse staff prepared and assembled 40 packets of information for the NIAMS Coalition Planning meeting on January 17.
- ◆ Clearinghouse staff made 149 coalition packets for advance mailing or use by the NIAMS during Coalition Week (March 27).
- ◆ Clearinghouse staff made 60 packets for the NIAMS to use at the Lupus Foundation of America NIH visit during Coalition Week.
- ◆ Graphics staff mounted numerous posters for the Intramural Research Program retreat.
- ◆ Clearinghouse staff developed signs and slides for the NIAMS Community Health Center meeting.

Next Steps:

- ◆ Continue to produce materials and provide meeting support for the NIAMS.

TASK 9: GRAPHIC DESIGN, PRODUCTION, AND REPRODUCTION SERVICES

Year 3 Activities:

Graphics staff members have played a key role in NIAMS Information Clearinghouse materials development. They have formatted new regular and large-print Questions & Answers and Handout on Health publications. In addition, they have converted Questions & Answers fact sheets into the new booklet format. Not only have they contributed to publications development, they have also created signs for several NIAMS meetings.

- ◆ Graphics staff formatted master copies of the following Questions & Answers publications into regular and large-print versions:
 - *Questions & Answers About Heritable Disorders of Connective Tissue*
 - *Questions & Answers About Sjögren's Syndrome*
- ◆ Graphics staff formatted a master copy of the new *Handout on Health: Scleroderma* publication into regular and large-print versions.

- ◆ Graphics staff completed cover designs for the following booklets:
 - *Do I Have Arthritis? (¿Tengo Artritis?)*
 - *The Many Shades of Lupus*
 - *Handout on Health: Scleroderma*
- ◆ Graphics staff updated master copies of the regular and large-print version of *How to Find Medical Information*.
- ◆ Graphics staff designed the inside illustrations for the new limited literacy booklet *The Many Shades of Lupus* and formatted a master copy of the regular print version.
- ◆ Graphics staff designed a brochure for the new NIAMS Community Health Center.
- ◆ Graphics staff designed the new Health Partnership Program stationery for the NIAMS.
- ◆ Graphics staff designed two issues (fall 2000 and spring 2001) of *IRPartners*, the NIAMS quarterly newsletter.
- ◆ Graphics staff designed the cover for the NIAMS 15th anniversary booklet.
- ◆ Graphics staff designed Spanish fact sheets for the Community Health Center, the Health Partnership Program, Sjögren's Syndrome, and Osteoarthritis.
- ◆ Graphics staff developed a style guide for use by all writers and editors involved in the creation/revision of Questions & Answers booklets.
- ◆ Graphics staff produced signage for the NIAMS Health Partnership Program and Intramural Research Program meetings.
- ◆ Graphics staff also completed other projects for the NIAMS:
 - NIAMS promotional flyer for the Sjögren's Syndrome booklet
 - NIAMS letterhead to reflect requested changes
 - NIAMS easy-to-read bookmark
 - NIAMS Spanish bookmark
 - NIAMS Information Clearinghouse Publication Order Form
 - NIH Pediatric Rheumatology Clinic erasers
 - NIH Pediatric Rheumatology Clinic pencils
 - NIH banner and other signs for NIAMS exhibits and health fairs
 - NIAMS pocket folders
 - NIAMS pens
 - NIAMS transparencies
 - Monitoring of NIAMS publications with the printer

Next Steps:

- ◆ Continue to provide support as needed.
- ◆ Continue helping with other projects as needed.
- ◆ Continue working on the redesign of the Questions & Answers fact sheets.
- ◆ Continue to provide the NIAMS with specifications as necessary for new, revised, and reprinted publications.
- ◆ Continue to oversee the printing process after Procurement has selected a printer.